

THE LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM

Task Force on Early Identification & Intervention

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Report to the Commission: Findings & Recommendations March 1, 2007

Summary of the Task Force Meetings:

The Early Identification & Intervention Task Force (EITF) held three public meetings. A total of 45 individuals (list attached) attended these day-long sessions (10AM-3PM.) Additional members of the public participated by teleconference access. Eleven of the task force participants (24%) were parents of individuals with ASD. The following areas of expertise were identified: intervention for ASD (15 individuals); early education (9); state agency (7); non-profit/foundation (7); legislative staff (7); healthcare(6); research (6); regional center/DDS (6); local programs (5). Attendance was excellent with 29 of the participants (64%) attending at least two of the sessions; fourteen members were present at all of the meetings.

The initial meeting (Nov. 14, 2006) was attended by 31 participants. Dr. Barbara Firestone provided welcoming remarks, introductions, a review of the Autism Commission, as well as leading a discussion on the goals, objectives, and timelines of the EITF. The EITF reviewed the existing systems of care for ASD. The group discussed and deliberated the strengths and gaps of these existing systems. The meeting concluded with the EITF prioritizing gaps that were deemed most important for future actions.

The second meeting (Dec. 13, 2006) was attended by 31 participants. The EITF discussed the most significant barriers to the early identification and intervention of ASD and deliberated the following:

- Were the gaps, barriers, and problems (and the state's role) all adequately defined?
- What are specific strategies to close these gaps and do they address such issues as resource allocation; feasibility of change; outcome measurements; potential for systemic changes that could benefit a larger population of children?
- Importance of identifying existing systems that are effective and successful models.
- Importance of addressing factors related to diversity, equity & cultural competence.
- Importance of identifying/engaging stakeholders, experts, & additional collaborators.

The final meeting was attended by 28 participants. **The EITF recommended that the following priority "gaps" should be addressed:**

1. *The appropriate screening, assessment, referral & intervention of children with ASD.*
2. *Helping parents to better access, utilize, & navigate complex systems of care.*
3. *Overcoming disparities & inequities in access to services for children with ASD.*
4. *Providing a seamless and integrated transition from regional centers to school districts at 3 years of age*

The EITF proposed solutions to these four priority “gap” areas that are comprehensive, multi-faceted, integrated, family-focused, community based and unequivocally linked to evidence-based best practices and outcome measures. In addressing certain problems, an incremental approach may be advised. Specifically, establishing a series of “demonstration/model” programs could not only establish their efficacy but also serve as “templates” for statewide expansion and replication. The EITF also emphasized that “professional development” was a critical and important overarching issue that impacted all of these priority “gaps.” The role of health plans and medical insurance companies in providing coverage for these assessments and interventions also requires future attention and clarification.

Discussion & Recommendations of Priority Problems:

Priority One: Improving the screening, assessment, & intervention of children with ASD

Overview:

Encouraging statistics indicate that children in California are now being referred at younger ages to regional centers for autism-related evaluations and services. Nevertheless, significant declines in the diagnosis of full-spectrum autism in school aged children have not occurred; thus suggesting that many children may be “slipping through the cracks.” Further, there is compelling evidence that parental concerns regarding early childhood development are often ignored by pediatricians and other health care providers. The National Survey of Early Childhood Health (NSECH) has established that almost half (47%) of parents report that their child has never received a developmental screening in the first three years of life. Only 42% of parents of children 0-3 were informed that a developmental assessment was being conducted and only 39% recalled the child was tested with specific tasks or skill requirements. (Halfon et al; “Assessing development in the pediatric office” Pediatrics; 2004; 113: 1926-33.) The American Academy of Pediatrics recommends that in addition to a general developmental screening tool, an autism-specific tool should be administered to all children at the 18-month visit since symptoms of autism are often present at this age, and effective early intervention strategies are available. (Pediatrics, Vol. 118 No.1 July 2006; pp. 405-420.) Other experts recommend testing at both 18 months AND at 24 months with an autism-specific tool. (<http://www.pediatrics.org/cgi/content/full/119/1/152>)

Major Barriers & Problems:

- Inadequate time and reimbursement to health care professionals
- 80% Pediatricians NO structured developmental screening evaluation
- 92% of pediatricians do NOT routinely screen for ASD
- Lack of reimbursement for non-medical staff & screening instruments
- Inadequate referral sources for assessment & intervention

Proposed Concept & Preliminary Recommendations:

Establish a series of demonstration (“model”) projects that would provide more effective “universal screening” for appropriate developmental milestones; with particular emphasis between 18-24 months of age. This proposal would include the following concepts:

- Partnerships with and links to established programs that are performing early developmental screening
- Improving communication and sharing of data/information between health care providers and community based services/programs
- Improved communication between the “medical home” & parents/families
- Integration of parents, childhood educators, & childcare providers in developmental screening programs
- Greater opportunities and incentives to health care providers

Proposed Analysis & Work Plan:

PROPOSAL	MODELS	EXPERTS	ALTER-NATIVES	OUTCOMES & COST	TRADE OFFS
Public-private partnerships	Kaiser-Santa Clara County Collaborative	Oregon Health Sciences Univ; dept of pediatrics	focus on CHDP; county health services;	>#children with being screened for ASD	may be difficult to replicate statewide
Structured universal screening	First5CA Special Needs Project	Nat.Acad.of State Health Policy; Child & Adolescent Health Measurement Initiative ; regional center service providers	established need for instrument-based developmental screening	># of kids receiving preschool services for special needs	> burden existing health care system
Pay-for-Performance	diabetes, asthma; hypertension	Dr. A Dudley UCSF; Dr M Rosenthal, Harvard	require instrument-based develop. screening	monitor services provided for children with special needs by health plans	need for monitoring and tracking outcomes
Improve “medical home” linkages	Lead Poisoning surveillance system? Communicable diseases?	Univ. Calif. Irvine Med. School; AAP; Commonwealth Fund	Training of parents & non-medical personnel; link with medical home	>detection of ASD & other special needs at younger age	> training, certification & monitoring. > personnel turnover

Priority Two: Helping Parents to better access, utilize, & navigate complex systems of care

Overview:

Parents, families, and caregivers presently have great difficulties in accessing, understanding and navigating the complex systems of services and programs that may be available to children with ASD. Although regional centers, educational systems and family resource systems all strive to provide parental assistance, effective community outreach is often challenging. Further, this information may be difficult to comprehend, unresponsive to special circumstances and complex problems. Potentially there are over 40 separate local and/or regional programs, most of which are categorical, that impact a child with ASD. Parents are further bewildered by the regional and local differences in these services and programs. The Task Force noted testimony that underscored the importance of closing these gaps in the current systems and providing information and

parental supports to all families, but particularly those living in diverse and underserved communities. A multi-state survey of 200 Latino families with disabled children indicated that 52% needed assistance on all items and issues that are measured by the “Family Needs Survey/Family Support Scale.”

Major Barriers & Problems:

- Complex systems of care for ASD
- Large number of programs/services (potentially over 40)
- Parents’ concerns are often dismissed (“just wait syndrome”)
- Lack of consistency in eligibility & access
- Cultural barriers
- Lack of data sharing and case management

Proposed Concept & Preliminary Recommendations:

To establish a statewide telephone “warm line” as well as other supporting resources that would include the following:

- A 1-800 statewide available number
- Website: “one-stop” roadmap of resources, programs, services
- Public information, multi-media campaign that would be linked to existing community resources and advocacy
- Culturally competent resources and information

Proposed Analysis & Work Plan:

PROPOSAL	MODELS	EXPERTS	ALTER-NATIVES	OUTCOMES & COST	TRADE OFFS
1-800 phone “warm-line”	Tobacco Early Start phone line	UCD school of public health	> resources to existing systems.	-Verify value; -Predict # calls/mos	-Increase demand. -more efficient use of existing services
Web-based resource center	DDS web site	?Kaiser system ?First 5CA	Child-care & preschool systems	Improve linkages to existing systems	>need for tech.; >”digital divide”
Ombudsperson Section	??resource centers	Regional centers; ARCA	County health; public health dept	Increased number of parent “mentor” volunteers	Another “parallel” bureaucracy
Print-based materials	??Asthma initiative?	Sonoma State;UCLA		> referrals from MDs & child care to regional centers	Local & regional differences; could be quickly outdated

Priority Three: Overcoming disparities & inequities in access to services for children with ASD

Overview:

The Task Force has received compelling and powerful testimony with regards to the pervasive and critical gaps that exist for children with ASD, and their families, who live in diverse and underserved communities. Cultural factors, stigma and other perceptions may foster misunderstandings of ASD as well as the possible mistrust of systems, programs and service providers that are intended to serve these children. A study in

Philadelphia (Dr. David Mandell, NIMH Conference; Oct. 2005) reported that, on the average, the diagnosis of ASD was delayed by almost 2 years among African-American children (7.5 years old) as compared to their Caucasian counterparts (5.5 years old.) Latino children diagnosed at ages intermediate between these two groups. African-American children with ASD are more likely to be misdiagnosed as having organic psychoses, mental retardation or selective mutism (Dr. David Mandell.) Researchers at The MIND Institute and other universities have established that autism encompasses a broad array of brain-based disorders and deficits. Despite these neuroscientific advances in the early detection and treatment of these disorders, such as Asperger's Syndrome, many children in underserved communities are not identified in a timely manner. This gap not only impedes the child's timely assessment and intervention but these delays may also have serious long-term consequences and adversely impact the child's outcome and prognosis.

Major Barriers & Problems:

- Cultural barriers, stigma & lack of information
- Lack of access to providers, services, programs
- Providers, services, programs lack cultural competency
- Lack of support services & transportation

Proposed Concept & Preliminary Recommendations:

Establish a series of demonstration ("model") programs for improved partnerships and collaboration with community based organizations to promote:

- Family and neighborhood based outreach, information & mentoring programs
- Community based professional development
- Oversight on implementation of ASD best practices
- Surveillance & monitoring of ASD

Proposed Analysis & Work Plan:

PROPOSAL	MODELS	EXPERTS	ALTER-NATIVES	OUTCOMES & COST	TRADE OFFS
Assess #s of qualified professionals	Compare services with demographics	Dr. David Bautista Hayes	>technology; Survey #s of professionals	>number of underserved children	>Disparities ("rob Peter to pay Paul")
CBOs (diversity advisory groups)	Asthma initiative; "promotora model"	foundations such as the CA Endowment	Existing county health department agencies	Leverage State dollars with additional foundation \$.	>challenges in organization, administration, oversight
ASD screen for infants & toddlers	Existing Early & Head Start Programs	Head Start childcare; preschool	parents and healthcare providers	> # of kids ~ ASD. ?Prop 10 funding?	> # suspect but not diagnosed with ASD.
>professionals underserved communities	"prime" UC ; outreach program	OSHDP	RC training ~ cultural competence	< waiting lists. ?? WIA & EDD funds	Drain resources & funding from other programs
Media outreach	Obesity Campaign	Foundations; media consultants	Community& faith based organizations	<stigma; more community-based activities	Why "ASD"??
Voluntary registry & data system	Cancer registry	Dr. Hirtz-Picciotto, MIND	Combine existing registries	Seamless information system on ASD.	Privacy concerns; HIPPA regulations; CDE regulations

Priority Four: Providing a seamless and integrated transition from regional centers to school districts at 3 years of age

Overview:

Families often face a crisis when children with ASD transition, at three years of age, from regional center services to school district programs. This transition disrupts programs; often at a crucial times when the child improving. This transition may occur without effective planning, case management, and communication. These inefficiencies squander precious resources and delay much-needed treatments. A definitive diagnosis of ASD may not be established by age three — even in children with serious developmental problems; thus potentially delaying desperately needed interventions. Regional centers and school districts also quarrel as to who should be paying for these services; services are delayed and children suffer. Most school districts are overwhelmed by a huge influx of students with ASD; preschool programs are often “in limbo.” School districts suffer from a lack of allocated funds and a dearth of administrative supports. One small school district (about 200 ASD students K-12) presently maintains 99 contracts with non-public schools and agencies at a cost of about \$3 million annually. Another district suffers a net deficit of over \$15,000 per each ASD preschool student annually. Concern was noted that all children in the Early Start Program must receive appropriate screening, assessment and intervention for ASD, as mandated by State law.

Major Barriers & Problems:

- Different eligibility for services
- Potential duplication and inefficiencies of programs, services and/or providers.
- Difficulties related to case management & communication
- Problems with compliance & oversight
- Difficulties in diagnosing ASD in children three years of age
- Regional centers & school districts argue over responsibility for services
- Many school districts lack resources and supports

Proposed Concept & Preliminary Recommendations:

To establish a multi-site demonstration (i.e. “model”) project to establish a seamless system for service delivery between regional centers and school districts for children with ASD from birth to kindergarten. This proposal would include the following concepts:

- Voluntary collaboration between regional centers and school districts
- “Pooled/shared” funding
- Diversity & Equity

Proposed Analysis & Work Plan:

PROPOSAL	MODELS	EXPERTS	ALTER-NATIVES	OUTCOMES & COST	TRADE OFFS
Extend Early Start to age 5 years	Other States	Regional centers Program managers & service providers SELPA	Other funding sources; ?Medical insurance?	> # ASD children in first 3 years. Possible savings?	May require legislation. ? > RC expenses?
Pooled/shared funds	Mt. Valley RC North Bay RC	Dr. Maher Dr. Cohen	Common providers; MOUs	Reduce special education by 10-20%	>more CDE funds for preschool programs
Best Practices	New York Standards	DDS Best Practices	IEP Process	<litigation & <fair hearings	Increased teacher training
Diversity & Equity	First 5CA Special Needs Project	FestivaEducative. Special Needs Network. Dr. Mangia	parent mentors; Diversity advisory board	Increased providers in underserved communities	>expenditures in community outreach